

Personal distress and sympathy differentially influence health care professional and parents' estimation of child procedure-related pain

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Running title: Emotional responses influence pediatric pain estimates

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ABSTRACT

Objective Caregivers' pain estimations may have important implications for pediatric pain management decisions. Affective responses elicited by facing the child in pain are considered key in understanding caregivers' estimations of pediatric pain experiences. Theory suggests differential influences of sympathy versus personal distress on pain estimations; yet empirical evidence on the impact of caregivers' feelings of sympathy versus distress upon estimations of pediatric pain experiences is lacking. The current study explored the role of caregiver distress versus sympathy in understanding caregivers' pain estimates of the child's pain experience. **Design, Setting, Subjects, & Methods** Using a prospective design in 31 children undergoing consecutive lumbar punctures and/or bone marrow aspirations at Ghent University Hospital, caregivers' (i.e., parents, physicians, nurses, and child life specialists) distress and sympathy were assessed before each procedure; estimates of child pain were obtained immediately following each procedure. **Results** Results indicated that the child's level of pain behavior in anticipation of the procedure had a strong influence on all caregivers' pain estimations. Beyond the impact of child pain behavior, personal distress explained parental and physician's estimates of child pain, but not pain estimates of nurses and child life specialists. Specifically, higher level of parental and physician's distress was related to higher child pain estimates. Caregiver sympathy was not associated with pain estimations. **Conclusions** The current findings highlight the important role of caregivers' felt personal distress when faced with child pain, rather than sympathy, in influencing their pain estimates. Potential implications for pain management are discussed.

Key words: distress; sympathy; child; parents; health care professionals; pain estimates

INTRODUCTION

Facing another in pain elicits a variety of responses in observers that may impact caregiving, and hence the sufferer's pain [1]. Among the variety of observer responses, observers' pain estimations are considered important in understanding caregiving responses such as decisions regarding provision of pain control or comfort. This is particularly important in the context of pediatric pain as children are highly dependent upon care from others. Indeed, preliminary evidence suggests that parental underestimation of child pain contributes to lower levels of parental comfort with administering pharmacological analgesics [2]. In contrast, increased parental vigilance for and associated higher estimates of child pain may contribute to more child health care use [3].

Empirical inquiry suggests that observers' differential affective responses elicited by another's pain are likely of key importance. Specifically, increasing evidence suggests that anticipating or observing another in pain is likely to elicit other-oriented affective responses such as emotional sharing or sympathizing with the other's pain experience but also self-oriented feelings of personal distress [1,4,5]. Both emotional responses are assumed to reflect the emotional component of an empathic response towards the person in pain. Pain-related empathy has been defined as "*a sense of knowing the experience of another person, including cognitive, affective and behavioral components*" [4, p. 286] and is influenced by characteristics of the observer (e.g. pain-related beliefs such as catastrophic thoughts about pain) and characteristics of the person in pain (e.g. pain expression) [4]. Previous findings suggest that both types of this affective component of empathy can occur together and are moderately correlated [4,6], yet may have differential consequences owing to their differential motivational quality [7,8]. The experience of personal distress when observing

another in need (e.g., feelings of anxiety and discomfort) is thought to originate from emotional contagion, thereby motivating primarily responses that are focused on reducing the observer's own aversive emotions and hence motivating actions attuned to one's own needs [9]. In contrast, other-oriented responses, commonly referred to as sympathy or putting themselves in the other's situation (i.e., perspective-taking), have been found to be associated with a more altruistic motivation to help another, and an engagement in care more attuned to the needs of the other person [7,8]. In the context of pediatric pain experiences in particular, caregivers' emotional distress response has been found to be key in explaining parental behavioral responses. Specifically, previous findings [e.g. 15] have shown that parental emotional distress is strongly influenced by their catastrophic cognitive appraisal of another's pain and mediates the relationship between this cognitive catastrophic appraisal and their engagement in behavioral protective responses.

Moreover, in adults, a differential impact of imagining yourself being in pain (i.e., self-perspective) versus sympathizing with another (i.e., other-perspective) in a painful situation upon emotional responses and pain estimates has been observed. In particular, while an other-orientated focus increased sympathy levels a self-oriented focus contributed to elevated levels of personal distress. Additionally, the self-orientated focus and associated distress resulted in higher and quicker ratings of personal pain compared to the other-orientated focus and associated sympathy [10,11]. The stronger impact of feelings of distress on personal pain reports might be due to a stronger elicitation of a fearful and/or aversive response that is more closely related to one's own actual experience of pain compared to imagining someone else being in pain [10,11]. Taken together, these findings suggest that the level of observers' experienced sympathy versus distress may also impact estimations of another's pain, yet,

clinical empirical evidence on the impact of caregivers' feelings of sympathy versus distress upon estimations of other's pain experiences is lacking.

The present study aimed at investigating the relationship between caregivers' distress and sympathy when being faced with child pain upon caregivers' estimation of child pain. We hypothesized that caregiver distress and sympathy when anticipating child pain would both impact pain estimates. Based on accumulating evidence showing a stronger impact of distress on personal pain ratings and behavioral responses towards another in pain [10,11,15], we hypothesize that particularly felt personal distress, rather than sympathy, will contribute to the pain estimates. Caregivers consisted of parents and health care professionals (HCP; i.e., physicians, nurses and child life specialists (CLS)) of children undergoing a series of consecutive painful medical procedures, i.e., lumbar punctures (LP) and/or bone marrow aspiration (BMA). Such procedures have been found to be particularly salient in eliciting emotional responses among caregivers [12]. Further, including a variety of caregivers (i.e., parents and various HCP) allowed exploring whether affective responses have a differential impact on pain estimates depending on the type of caregiver. This may further our understanding of previously observed discrepancies between parent and HCP's child pain estimates and the subsequent impact on pain management decisions¹³. In addition, since pain expressions have been identified as a major determinant of caregivers' pain estimates [1,4,14], the above-hypothesized relationships were examined whilst also controlling for the impact of the child's pain expressions.

METHOD

Participants

The present study reports on the longitudinal part of the “Ghent - Pain in Child Leukemia - study” (“G-PICL study”) for which ethical approval was obtained from the Ethics Committee of Ghent University Hospital. Data on the impact of parental catastrophic thinking on their emotional and behavioral responses to child pain are described elsewhere [15,16]. The present study reports on a unique part of this study aimed at the prospective investigation of parental and health professional’s pain estimates during consecutive lumbar puncture (LP) or bone marrow aspirations (BMA). Participants were children recently diagnosed with leukemia at Ghent University Hospital who could speak and write Dutch, did not have any pre-existing developmental delay, and did not experience a relapse or received bone marrow transplantation. Of the 42 invited families, six refused participation (85.71% response rate), mainly due to being overwhelmed with the diagnosis. Five families were excluded from analyses due to not following the standard protocol for LP/BMA procedures ($N=4$) or undergoing bone marrow transplantation ($N=1$). The final sample of 31 participating families (17 boys, 14 girls) included 25 children diagnosed with Acute Lymphoblastic Leukemia (ALL) and six with Acute Myelogenous Leukemia (AML). Mean age of the children was 6.50 years ($SD=4.10$, range=0.6-15).

For the majority of the LP/BMA procedures only one of the parents was present (81.3%) and data were obtained from either the mother (64.6%) or the father (16.7%). For 7.9% of the procedures both parents were present, for 1.3% another person (e.g. grandparent) was present and for 9.5% of the procedures no parent or other family member was present. The mean age of mothers and fathers was 35.65 years ($SD=5.74$, range=23-47) and 39.40 years ($SD=5.45$; range=32-50), respectively. Most parents were married or co-habiting (85.7%). All families were Caucasian with the majority having the Belgian nationality 96.4% ($N=27$).

During the time of the study a total of 18 physicians ($N=15$ (83.33%) female; mainly pediatricians in training) responsible for performing LP/BMA procedures, 49 nurses ($N=46$ (93.88%) female; $M=7.08$ years employment at the department; $SD=6.86$; range=0–28.37), and five female child life specialists (CLS; $M=7.66$ years of employment at the department; $SD=6.08$, range=0.06–14.91) were working at the department.

Procedure

Families who met the inclusion criteria were consecutively invited three to seven days after being diagnosed. All families were reassured that non-participation would have no influence on their treatment in the clinic and that withdrawing participation was possible at any time. Written informed consent was obtained from the parent and written assent from children older than 12.

Each LP/BMA procedure the child had to undergo, as part of their treatment protocol, was consecutively included in the study. One hour before the LP/BMA procedure an aneutectic mixture of local anesthetics lidocain and prilocaine was applied to the child's skin¹⁷ and a mixture of nitrogen peroxide-oxygen¹⁸ was administered to the child through a facial mask during the procedure. At least three staff members were present during LP/BMA procedures: 1) the physician performing the procedure, 2) a nurse responsible for preparations and aftercare, and 3) a CLS administering the nitrogen peroxide-oxygen and promoting child coping behavior (e.g., providing information, distraction). Standard procedures at Ghent University Hospital allowed parents in the treatment room during preparations and aftercare, but asked parents to wait outside *during* the actual LP/BMA procedure.

Measures

Distress and sympathy

Before each LP/BMA procedure, the parent, physician, nurse and CLS, rated their own level of personal distress (“*Specify how anxious you are at this moment*”) and sympathy towards the child (“*Specify to what extent you can sympathize with the feelings of the/your child at this moment.*”) on an 11-point rating scale ranging from 0 (not at all) to 10 (a lot). This operationalization of sympathy and distress is conform to the assessment applied in previous studies in the context of pain and social psychology [7,8] and is thus expected to reflect the theoretical distinction between distress and sympathy as explained in the introduction.

Pain estimation

After each LP/BMA procedure, the parent, physician, nurse and CLS rated the child’s pain level (“*Specify how much pain you think the/your child experienced during the LP/BMA procedure*”), on an 11-point rating scale ranging from 0 (not at all) to 10 (a lot).

Child pain behavior

Children’s behavior during preparations (i.e., before the start of the LP/BMA procedure) was videotaped allowing coding of children’s pain behavior in anticipation of the LP/BMA procedure. Child pain behavior was coded using an adaptation of the coding procedure developed by Walker and colleagues (2006) [19] (see Caes and colleagues (2014a) [15] for more details). Of relevance for the current analyses, is the occurrence of child verbal and non-verbal pain behavior, defined as behavior focusing on the pain experience (e.g., “I don’t

want to do this, I'm scared'', 'It will hurt a lot'', crying, screaming, resisting), rated as occurring (=1) or not occurring (=0) for each 5s interval [20]. Two independent coders assigned codes to half of the tapes, with 20% overlapping tapes to calculate inter-rater reliability. Kappa reliability coefficients indicated good inter-rater reliability (.76-.94) [21]. To control for the varying length of the preparations, the total score for child verbal and non-verbal pain behavior was divided by the total amount of time intervals and multiplied by 100. A mean score of child verbal and non-verbal pain behavior was calculated.

Data analysis

The data of the present study are hierarchically nested, with parental pain estimates for each LP/BMA procedure (level one) nested within individuals (parents; level two), which are in turn nested within couples (mother and father of a particular child; level three). Similarly, pain estimates by HCP for each LP/BMA procedure (level one) are nested within individuals (i.e., child, level two). Therefore, data were analyzed by means of multilevel modeling (HLM version 6.01) [22] as this method explicitly accounts for the dependency of the individual observations allowing more precise parameter estimates [23]. Moreover, multilevel analysis does not require an equal number of observations, which allowed us to retain all cases in our analyses even though we do not have data of both parents and all three HCP for every procedure [24].

The following set of multilevel regression analyses was run with pain estimates as the dependent variable and all independent continuous variables standardized and grand mean centered, as this allows more coherent interpretations of the coefficients. In a first step, the baseline model, without any predictors except 'time' (i.e., the number of the LP/BMA

procedure, e.g., first=0, second=1, etc.), was run to calculate the level of variance in pain estimations at each level. In the second step, we added the first level variables (i.e., child pain behavior, distress and sympathy for each procedure). For parental pain estimates only, the third step consisted of entering parent sex (level two) into the model. Lastly, child age, sex and diagnosis (AML or ALL) were added as third level (for parents) or second level (for HCP) variables. To obtain the best fitting model, the likelihood ratio deviance test was used to determine if the final model should include random slopes of first level variables. For all models, the model with fixed effects was the best fitting, most parsimonious model (all $\chi^2_{(14)} < 24$, *ns*). For parent data, the slopes for the effect of the first and second level variables were fixed on the third level because dyads do not have enough lower-level units to allow the slopes to vary [23]. In addition to reflecting the best fitting model, keeping the slopes fixed also accounts for the smaller sample size on second or third level as this smaller sample size reduces the power of detecting random slopes [25]. For all analyses full maximum likelihood estimation was used and the effect size r , with $r=.10$ a small, $r=.30$ a medium and $r=.50$ a large effect, was calculated [23].

RESULTS

Descriptive statistics

Mean levels of all variables are shown in Table 1. A total of 306 LP/BMA procedures were observed, with the most frequent procedure being LP (62.2%), followed by BMA (27.6%) and both procedures consecutively (5.7%). On average, a child received ten LP/BMA procedures (range=4-14) over the course of its treatment. In accordance with [25], the 306 observations constitute the sample size to be considered to determine the current study to be well powered to explore the impact of the level 1 variables distress and sympathy.

The average level of child pre-procedural pain behavior was 11.72 ($SD=17.87$, range=0.00–92.95). Parents reported significantly more personal distress compared to all HCP (all $t_{(60)} > 6.25$, $p < .001$) and higher sympathy levels than nurses ($t_{(60)}=2.54$, $p<.05$). CLS also reported significantly more sympathy towards child pain compared to nurses ($t_{(60)}=2.71$, $p<.05$).

Caregiver distress and sympathy was only moderately correlated for parents ($r=.16$, $p<.01$).

Parent's and nurse's reported level of distress was weakly, but significantly, correlated with child pain behaviors before the procedure ($r_{\text{parents}} = .35$, $p < .01$; $r_{\text{nurses}} = .21$, $p < .01$).

Similarly, parental sympathy showed a weak, significant correlation with child pain behaviors before the procedure ($r = .21$, $p < .01$). No significant correlation was found between child pain behaviors on the one hand and nurse's level of sympathy, physician's and CLS's level of distress or sympathy on the other hand (all $r < .12$, ns). Pain estimations did not differ between the respondents (all $t_{(60)} < 1.88$, ns).

- Insert Table 1 about here -

The impact of distress and sympathy on pain estimations

Findings for the final models for parents, physicians, nurses and CLS can be found in Table 2.

Parents. The intercept model indicated that 35.92% of the variance in parental pain estimations was on the third level (between parent-child dyads), 56.62% was found on the second level (within parent-dyads) and 7.45% on the first level (within parents). We found a significant effect of personal distress ($\gamma_{200}=.49$, $t_{(120)}=2.22$, $p<.05$, $r=.19$), indicating that parents who are more distressed before the LP/BMA procedure make higher pain estimates. Furthermore, child pain behavior significantly influenced parents' pain estimates ($\gamma_{400}=.53$,

$t_{(120)}=3.00, p<.01, r=.25$), such that higher levels of child pain behavior were related with higher child pain estimates by parents (see Table 2 for the final model estimates).

Physicians. The intercept model for physicians indicated that 95.68% of the variance in their pain estimations was on the second level (between children), while 4.32% of variance was found on the first level (within physicians). Physician's personal distress experience showed a significant effect ($\gamma_{20}=.41, t_{(188)}=4.23, p<.001, r=.29$), with higher physicians' estimates of child pain when they experienced more personal distress. Furthermore, child pain behavior ($\gamma_{40}=.36, t_{(188)}=2.25, p<.05, r=.16$), and child diagnosis also showed a significant impact ($\gamma_{02}=.92, t_{(24)}=3.12, p<.01, r=.36$), indicating that physicians estimated the pain higher when children exhibited more pain behavior and if children were diagnosed with AML (see Table 2).

Nurses. The intercept model for nurses indicated that 73.29% of the variance in their pain estimations was on the second level (between children) and 26.71% on the first level (within nurses). Only child diagnosis showed a significant effect ($\gamma_{02}=1.00, t_{(24)}=2.34, p<.05, r=.32$) indicating that nurses provided higher pain estimates for children diagnosed with AML (see Table 2).

CLS. For CLS the second level variables (between children) accounted for 78.85% of the variance in their pain estimations and first level variables for 21.15%. Child pain behavior ($\gamma_{40}=.39, t_{(189)}=2.73, p<.01, r=.12$), and child diagnosis ($\gamma_{02}=1.82, t_{(24)}=5.29, p<.001, r=.55$) showed a significant impact on CLS' pain estimates. These results suggest that CLS rated the child's pain higher when the child showed more pain and was diagnosed with AML.

- Insert Table 2 about here -

DISCUSSION

The current study examined the role of personal distress versus sympathy on caregivers' pain estimates using a prospective design in children undergoing painful LP/BMA procedures. The results were partially in line with expectations indicating that higher levels of distress in anticipation of the procedure were related to higher pain estimations, yet this was only the case for parents and physicians. As such, our findings extend previous ones indicating that when personal distress is high, these feelings do not only contribute to increased personal pain reports [10], but also increased estimations of *another's* pain. Personal distress was not related to pain estimates for nursing staff and CLS. Feelings of sympathy for the child's pain did not show an influence on the level of pain estimated by any of the caregivers. These results suggest that caregivers' level of distress elicited by anticipating a child undergoing a painful experience, rather than their feelings of sympathy, influence caregivers' pain estimates.

While elevated estimates of pain may contribute to an adaptive caregiver's response of increased pain management and protective responses, it may also put caregivers at risk for heightened and/or prolonged engagement in protective behavior (e.g., heightened usage of health care; child reassurance) that may have maladaptive effects on child outcomes, such as heightened child distress and pain [15,20]. Preliminary evidence within adult couples supports these assumptions by indicating that a perspective-taking manipulation (i.e., imagining and concentrating on how the other feels during the pain task) was related to lower pain ratings in the partner undergoing the pain task [26]. Research has also shown that elevated levels of protective behaviors may give rise to child perceptions of help being unhelpful or "miscarried" [27]. Indeed, it has been suggested that heightened self-focus of

distressed (and protective) parents may put parents at risk for being less attuned to the needs of the child [28], while, higher levels of sympathy have been associated with more accurate perceptions of the needs within a social situation [11]. Furthermore, high levels of protective behaviors might also hamper the pursuit and attainment of other important child goals [29].

Although future studies are needed to investigate the link between pain estimates and pain management decisions, it is likely that caregiver's pain management behavior will be driven by their pain estimates. Consequently, it is plausible to assume that educating caregivers about pain assessment, mechanisms underlying pain estimations and subsequent pain management, and addressing any misconceptions or fears surrounding various pain management techniques could potentially be beneficial for providing effective pain management [30]. Aside or complementary to education, teaching emotion regulation techniques (e.g., mindfulness- and acceptance-based approaches or utilizing attention deployment to change perspective-focus from self to the other) to cope with elevated levels of personal distress could be valuable in supporting caregivers who are confronted with (repeated instances of) child pain.

Further research is needed to examine why only distress, and not sympathy, was related to pain estimates. One tentative explanation is that estimating child pain might be a primary appraisal of the painful situation (e.g., presences and intensity of pain) and therefore mainly influenced by the threat of pain and associated self-oriented distress [5]. It is plausible that sympathy could play a more important role in more elaborate, reflective appraisals influencing pain management decisions (e.g., observer evaluation of the child's ability to cope with pain, impact of pain on daily activities, the child's need for help).

Interestingly, findings of the present study revealed that the association between distress and pain estimates was dependent on the caregiver's relation to the child (i.e., only evident for parents and physicians, not for nursing staff or CLS), and hence suggest that distress may not always be equally important in understanding caregiver pain estimates. A number of tentative explanations may account for these differential relationships. For instance, as the physicians performing the LP/BMA procedures rotate to another department after six months, nurses and CLS might have more experience with both the general aspects of LP/BMA procedures as well as a particular patient's response to these procedures. This extended experience might influence their adaptation to these procedures (i.e., their level of distress) and pain estimates [31,32]. Although more research is needed to replicate these differential patterns depending on the caregiver role, knowledge on differences in emotional responses between caregivers and the impact on their pain estimations could further our understanding of the discrepancies between caregivers' pain estimates [13].

Some small differences were found in factors influencing pain estimations amongst the various caregivers. Specifically, all HCPs provided higher pain ratings for children diagnosed with AML compared to children diagnosed with ALL. As this difference was not the primary goal of our investigation we have no specific supporting theory, but a number of differences between both diagnoses may account for differential pain estimates. First, although children with AML generally underwent less LP/BMA procedures ($M_{AML}=6$ versus $M_{ALL}=11$), LP/BMA procedures were more often combined in children with AML (35.3% of the procedures compared with 1.2% in children with ALL). Second, children with AML have lower survival rates [33] and receive a more intensive treatment protocol [34]. In particular, HCP, but not parents, were aware that children with ALM receive a more toxic chemotherapy treatment with potential stronger side effects compared to children with ALL. Although more

inquiry is needed on how these explanations may account for higher pain ratings for children with ALM amongst HCP, it is plausible to assume that this knowledge by HCP might play a substantial role.

This study is not without limitations. First, the level of experience of HCPs with LP/BMA procedures or caregivers' own personal experiences with painful procedures was not assessed and could therefore not be taken into account in the analyses. Second, some specific aspects related to the procedure that could influence caregivers' estimations of child pain were not assessed (e.g., child's verbal or non-verbal pain-attending behavior during the procedure, the information health care providers shared with parents about the procedure's flow and child reactions). Third, caution is needed as our data do not allow determining whether caregivers' pain estimations are an accurate reflection of the child's pain experience or rather represent an over- or underestimation. Fourth, although in line with previous assessment strategies and theoretical suppositions, the use of a single item to assess caregiver distress and sympathy might be limited in capturing the full quality of caregiver's emotional response. Lastly, the impact of the pain estimations on subsequent caregivers' pain management decisions (e.g., soothing, administering pain medication, distraction) could not be explored in the current study and requires future research attention.

CONCLUSION

The current study highlights the importance of caregivers' emotional response, distress in particular, in understanding caregivers' estimations of a child's painful experience.

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Table 1: Mean scores, standard deviations and range of LP/BMA-related measures.

	Distress			Sympathy			Pain estimates		
	<i>M</i>	<i>SD</i>	<i>range</i>	<i>M</i>	<i>SD</i>	<i>range</i>	<i>M</i>	<i>SD</i>	<i>range</i>
1. Parents	3.98	2.64	0-10	6.96	1.98	1-10	4.34	2.39	0-10
2. Physicians	2.03	1.46	0-7	6.07	2.31	0-10	3.39	2.08	0-10
3. Nurses	1.35	1.47	0-7	5.66	2.05	0-10	3.96	2.38	0-10
4. CLS	1.42	1.79	0-10	6.98	1.78	1-10	3.35	2.19	0-10

Note. CLS = Child life specialists